Connecting for Better Health Meeting

June 27, 2024
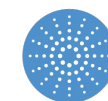
Agenda

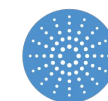| No.	Item	Minutes
1	Welcome and Introductions	5 minutes
2	Federal Updates ● HHS Final Rule to Establish Information Blocking Disincentives for Health Care Providers ● Federal Privacy Legislation: American Privacy Rights Act	15 minutes
3	State Updates ● California State Legislation Tracking ● Budget Update	10 minutes
4	Data Exchange Framework Community Sandbox Demonstration	25 minutes
5	News, Events, and Announcements	5 minutes

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Advancing data sharing to improve the health of all Californians

About The Coalition

Our Vision: Every Californian and their care teams have the information and insights they need to make care seamless, high quality and affordable.

Policy Priorities

- **DSA Education & Implementation:** Promote awareness of the DSA and support data exchange implementation to realize the promise of AB 133

- **Funding:** Advocate for the state to dedicate continued funding for health and social services data sharing and encourage state agencies to seek federal match when and where appropriate

- **Integration of social services data:** Develop and communicate case studies and policy recommendations that support cross-sector data sharing, consent, and authorization

- **Advance DxF Governance, Enforcement, and Accountability:** Work towards the passage of DxF legislation, monitor state legislation and budgetary actions related to data sharing, and provide critical feedback to CDII and other state agencies to resolve challenges

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Federal Updates

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HHS Final Rule: Information Blocking Disincentives for Health Care Providers

The [HHS final rule published on June 24](#) establishes the following disincentives for providers participating in the following Medicare programs:

- **Medicare Promoting Interoperability Program:** Hospitals found to be information blocking will not be considered meaningful EHR users, leading to a loss of potential financial rewards

- **Merit-Based Incentive Payment System (MIPS):** Eligible clinicians found to be information blocking will not be considered meaningful EHR users, resulting in a zero score in the Promoting Interoperability performance category, potentially lowering their overall MIPS score and impacting their reimbursement *(January 1, 2025 effective date)*

- **Medicare Shared Savings Program (MSSP):** Accountable Care Organizations (ACOs) found to be blocking information may be excluded from the program for at least a year, forfeiting potential revenue

Furthers **21st Century Cures Act** implementation by building upon the [2023 OIG Final Rule](#), which establishes information blocking penalties for health IT entities.

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Status Update & Overview of the American Privacy Rights Act

June 27, 2024

Jen DeAngelis

Director of Federal Policy & Advocacy

Blue Shield of California

Agenda

Setting the Scene

Action in 2024

What's in the American Privacy Rights Act?

Resources

Setting the Scene

- Sense that Congress is long overdue to act on a comprehensive, national privacy law.
  - Attention on the proliferation in the use and implications of artificial intelligence across sectors is both driving and distracting from the privacy debate.

- Key members:
  - Representative Cathy McMorris-Rodgers (R-WA), Chair of the House Energy & Commerce Committee
  - Senator Maria Cantwell (D-WA), Chair of the Senate Commerce Committee

- Much of the energy behind privacy reform legislation has been driven by Rep. McMorris-Rodgers, who is retiring at the end of the year and considers privacy reform a legacy issue.

- Currently little interest or buy in in the Senate to take on a major privacy reform bill.

- Given the number of persisting concerns from Members & stakeholders about the pending legislation (the American Privacy Rights Act), it is unlikely the bill moves at the end of the year.

Action in 2024

- **April 7**: Rep. McMorris-Rodgers and Sen. Cantwell released a discussion draft of the American Privacy Rights Act (APRA)

- **April 17**: House Energy & Commerce Subcommittee on Innovation, Data, and Commerce hearing, "Legislative Solutions to Protect Kids Online and Ensure Americans' Data Privacy Rights"

- **May 8**: Senate Commerce Subcommittee on Consumer Protection, Product Safety, and Data Security hearing, "Strengthening Data Security to Protect Consumers"

- **May 23**: House Energy & Commerce Committee Subcommittee on Innovation, Data, and Commerce markup: APRA passes out of Subcommittee by voice vote (unanimous)

- **June 25**: House Energy & Commerce Chair McMorris-Rodgers & Ranking Member Frank Pallone (D-NJ) introduce revised American Privacy Rights Act (H.R. 8818)

- **June 27**: House Energy & Commerce Committee Full Committee markup: **CANCELLED!**

What's in the American Privacy Rights Act (H.R. 8818)?

Big Picture: The American Privacy Rights Act aims to establish a federal framework that expands consumer privacy rights, establishes data security standards, and establishes enforcement mechanisms for privacy and data security violations. The goal is to establish (1) a uniform, national privacy and data security standard in the U.S.; and (2) expressly preempt State and local laws.

Key Provisions:

- Data Minimization (Sec. 102):
    - Covered entities would not be allowed to collect, process, retain, or transfer covered data beyond what is necessary, proportionate or limited to provide or maintain a product or services required by an individual.
    - Covered entities would not be allowed to collect or transfer biometric or genetic information or "sensitive data" to a third party without an individual's affirmative express consent unless allowed by a permitted purpose.

- Transparency (Sec. 104):
    - Covered entities would be required to make publicly available, in a clear and conspicuous and easy-to-read privacy policy that provides detailed representation of the data collection, processing, retention, and transfer activities of the covered entity.
    - The bill would require that privacy policies of disclose: the categories of data collected, processed, or retained; the purposes for the data processing; whether the covered entity transferred covered data, why such data is transferred, and the name of any data brokers to which data is transferred, among other details.

What's in the American Privacy Rights Act? Continued

- <u>Consumer Controls (Sec. 105)</u>:
    - The bill would provide individuals the right to access (a) covered data that is collected, processed or retained by a covered entity; (b) the name of any third party or service provider to which the data was transferred; and (c) the purpose of the transfer.
    - A covered entity must correct inaccurate or incomplete covered data, delete covered data, and export covered data of an individual upon request.

- <u>Opt-out Rights (Sec. 106)</u>:
    - The bill would require covered entities to provide consumers the right to opt out of the transfers of covered data to third parties as well as to opt out of the use of their personal information for targeted advertising via a clear and conspicuous mechanism.
    - The FTC Commissioner would be required to establish requirements & technical specifications for opt-out mechanisms that allow individuals to exercise their opt-out rights through a single interface and provides a mechanism for an individual to selectively opt out of the collection, processing, retention or transfer of covered data by a covered entity.

Prior versions of APRA included provisions that would allow individuals the option to opt out of certain algorithms or algorithmic tools that are used by covered entities for "consequential decisions" related to housing, employment, and health care, among other issues. These provisions have been removed in the most recent bill draft.

What's in the American Privacy Rights Act? Continued

- <u>Data Security (Sec. 109):</u>
  - Each covered entity would be required to implement data security practices that would include (at a minimum): routine risk assessments; disposing of covered data as required or that is no longer necessary for the purpose it was collected; and implementing procedures to detect, respond to and recover from data security incidents; among other requirements.

- <u>Enforcement (Secs. 115, 116, 117) :</u>
  - The bill establishes enforcement authorities for the Federal Trade Commission, State Attorneys general, and individuals.
  - Individuals would be permitted to file civil lawsuits against covered entities that violate their rights under the Act and recover damages.
  - The bill establishes that mandatory arbitration agreements are not valid or enforceable in instances where the alleged violation resulted in a "substantial privacy harm" or involved a minor.

- <u>Preemption (Sec. 118):</u>
  - No state may adopt, enforce, or continue in effect any law, regulation, rule, requirement, prohibition or standard "covered by" the provisions of the Act, with delineated exceptions notably "laws that protect the privacy of health information, healthcare information, medical information, medical records, HIV status, or HIV testing".
  - Covered entities that are required to comply with other specified Federal privacy laws and regulations -- including the HITECH Act, HIPAA, and 42 CRF Part 2 -- are not subject to the American Privacy Rights Act.

Resources

- Bill Text (H.R. 8818):
https://www.congress.gov/bill/118th-congress/house-bill/8818/text?s=1&r=1&q=%7B%22search%22%3A%22hr+8818%22%7D

- Section-by-Section Summary:
https://d1dth6e84htgma.cloudfront.net/APRA_Section_by_Section_026cc46a2c.pdf

- Congressional Research Services Report (updated May 31):
https://crsreports.congress.gov/product/pdf/LSB/LSB11161

- Bill Texts and Filed Amendments for Cancelled June 27 Markup:
https://docs.house.gov/Committee/Calendar/ByEvent.aspx?EventID=117487

Questions

State Updates

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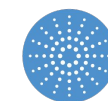
California Legislation Tracking (1/2)

No./Author	Summary	Recent Developments
AB 236 (Holden)	Requires health plans and insurers to annually verify and delete inaccurate listings from provider directories to be at least 60% accurate, with administrative penalties for failure to meet benchmarks. Authorizes DMHC and Department of Insurance on or before 2025 to develop uniform formats for plans and insurers to request directory information from providers and establish methodology and processes to ensure accuracy.	Amended by author (6/18); Referred to Sen. Health Committee
AB 1011 (Weber)	Imposes new restrictions on the sale, disclosure of "social care Information" on users of "closed-loop referral systems" including public agencies, non-profits, health care providers, vendors.	Two-year bill in Sen. Appropriations
AB 1331 (Wood)	Establishes DxF governing board; outlines appointment of members; requires board approval for any amendments to DSA; requires QHIOs to be non-profits; decrease size of board to five members; require certain reports and educational efforts related to consumers and data; among other requirements.	Two-year bill in Sen. Appropriations
SB 294 (Wiener)	Requires health plans and disability insurers to automatically submit upheld grievance decisions to the Independent Medical Review System within 24 hours, along with relevant information.	Referred to Asm. Appropriations (6/5); Hearing postponed (6/26)
SB 957 (Wiener)	Requires the CDPH to collect sexual orientation, gender identity, and variations in sex characteristics/intersex status (SOGISC) data from third-party entities, including local health jurisdictions, on any forms or electronic data systems unless prohibited by federal or state law. This bill would only require health care providers to disclose SOGISC information that is voluntarily self-identified and prohibit disclosures for individuals under 18 years of age.	Passed Asm. Health Committee (6/18); Referred to Asm. Appropriations (6/24)

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California Legislation Tracking (2/2)

No./Author	Summary	Recent Developments
SB 1016 (Gonzalez)	Requires CDPH by 2027 to use the OMB demographic collection categories for Hispanic and Latino groups, use separate categories for each major Latino group and Mesoamerican Indigenous nation not included in OMB standards, and include specific languages when collecting preferred language.	Passed Asm. Health Committee and referred to Asm. Appropriations (6/12)
AB 2198 (Flora)	Delays when specialized insurers that offer dental or vision services, excluding Medi-Cal dental managed care, from federal API requirements for health plans and insurers to 2027 or when the federal rules are implemented, whichever is later.	Referred from Sen. Appropriations to second reading on Sen. Floor pursuant Senate Rule 28.8 (6/24); Ordered to third reading (6/25)
AB 2250 (Weber)	Establishes SDOH screeners as a covered benefit for Medi-Cal beneficiaries and require health plans and insurers to cover SDOH screenings. Additionally, requires providers to use specified tools or protocols to document patient responses and require health plans and insurers to provide PCPs access to peer support specialists, lay health workers, social workers, or CHWs.	Placed on suspense file in Sen. Appropriations (6/17)
AB 1943 (Weber)	Requires DHCS to produce a report on telehealth in Medi-Cal, including telehealth access and utilization; effect of telehealth on timeliness, access, and care quality; and effect of telehealth on clinical outcomes. Authorizes DHCS to issue policy recommendations based on report findings.	Placed on suspense file in Sen. Appropriations (6/17)
AB 2058 (Weber)	Requires legible disclosures on devices that collect or analyze medical or physiology information regarding effectiveness limitations for the device's intended population considering patient characteristics, including age, color, disability, ethnicity, gender, or race. Infractions are considered to be a criminal by 2027.	Amended by author; Referred to Sen. Health Committee (6/24)

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California Legislation Tracking - Artificial Intelligence

No./Author	Summary	Recent Developments
SB 892 (Padilla)	Requires the Department of Technology to establish an AI risk management standard as specified, which would include a risk assessment and equity assessment for automated decision systems.	Amended and referred to Asm. Privacy & Consumer Protections Committee (6/21)
SB 893 (Padilla)	Establishes the California Artificial Intelligence Research Hub to facilitate collaboration between government agencies, academic institutions, and private sector partners.	Amended and referred to Asm. Privacy & Consumer Protections Committee (6/21)
SB 896 (Dodd)	Requires the State to produce a Benefits and Risks of Generative Artificial Intelligence Report, perform a joint risk analysis of potential threats, and notify individuals of AI communications.	Amended and re-referred to Asm. Privacy & Consumer Protections Committee (6/4)
SB 1047 (Weiner)	Defines "AI models" and establishes requirements for AI developers to implement safety and security protocol and submit certification of compliance with penalty for perjury, and prohibit AI use if unreasonable risk that could cause or enable harm. Limits to no monetary penalties for violations before July 1, 2025 and no civil penalties for violations before January 1, 2026.	Amended and passed Asm. Privacy & Consumer Protections Committee; Referred to Asm. Judiciary Committee (6/20)
SB 1120 (Becker)	Establishes requirements for health plans and insurers using algorithms and AI decision making tools for utilization review or utilization management decisions. Violations are considered to be a crime.	Amended and passed Asm. Health Committee; Referred to Asm. Privacy & Consumer Protections Committee (6/20)
AB 3030 (Calderon)	Requires health providers using AI for patient communications related to clinical information to include AI disclaimers specific to the mode and clear instructions connecting them with a human health care provider. Violations are considered to be a crime.	Amended by author (6/18) and passed Sen. Health Committee (6/26)
AB 2013 (Irwin)	Requires AI developers to publicly post by 2026 a high-level summary of the datasets used to train their AI with minimum reporting elements specified and a synthetic data generation disclosure. Includes exceptions for AI with certain purposes and for AI developed before 2025.	Amended by author (6/17) and passed Sen. Judiciary Committee (6/26)
AB 2930 (Bauer-Kahan)	Requires automated decision tool developers and deployers to perform impact assessments, share results with the state but exempt from CA Public Records Act, notify impacted individuals, accommodate information corrections and requests, prohibits AI that has reasonable risk discriminate, and authorizes civil action for violations. Requires state agencies using automated decision tools that make consequential decisions to disclose tools used and comply with the deployer requirements.	Amended by author and referred to Sen. Judiciary Committee (6/24)

Budget Update

State budget agreement announced by Gov. Newsom and legislative leaders on June 22

- Details of budget package released – Addresses $46.8B budget deficit by reducing spending and pulling over $12B from reserves
- **Health Care Data Infrastructure Impact:** Cuts remaining Equity and Practice Transformation (EPT) Payments

Budget Act of 2024 (AB 107) signed by Gov. Newsom on June 26

- New state fiscal year begins on July 1
- Negotiations on trailer bill language can continue into July and August

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Data Exchange Framework Community Sandbox

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Overview of DxF Community Sandbox

What It Is: A dynamic learning environment for organizations participating in California's statewide Data Exchange Framework (DxF) to securely and rapidly test, collaborate, and scale new workflows and strategies to realize the value and promise of the DxF.

Accelerate DxF Adoption

The DxF Community Sandbox provides a virtual onramp that **allows organizations with differing systems** and **data management platforms** to readily **participate in a test environment that mirrors the real world**

Produce Shared Assets

The DxF Community Sandbox **allows for the capturing of shared learnings** and **publishing use cases** with **corresponding synthetic test data**
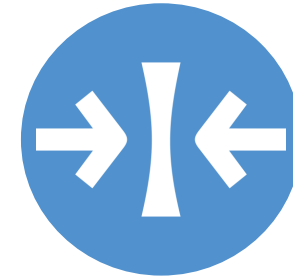
Identify Tech & Policy Gaps

The DxF Sandbox **develops a shared understanding and agenda among policy makers, regulators, and those implementing the DxF** of **major obstacles** that **require technology or policy intervention**

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Why Project Sandbox?

Create implementation guidelines for DxF rollout that correspond to high-priority use case

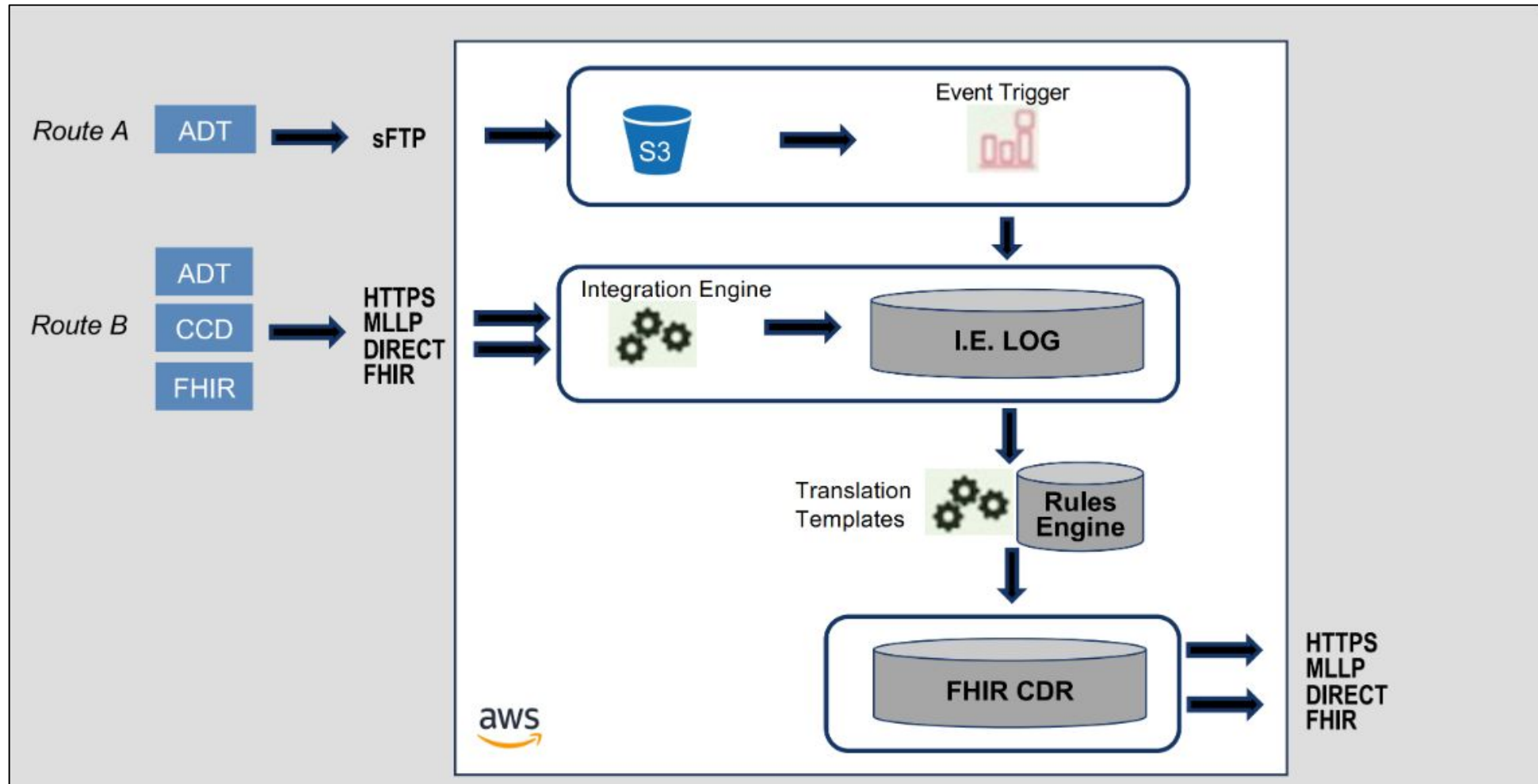Prove out high priority use cases and show how the DxF accommodates social care integration and whole-person care

Demonstrate how partners and competitors are able to collaborate to keep the person at the center and share only the data needed

Illustrate how DxF meets state's vision for data exchange and allows for new entrants (eg. EMS, justice, and education)

powered by aws

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DxF Sandbox Functional Architecture

DxF Sandbox Co-Design Team

Early Adopters

QHIOs and other invitees
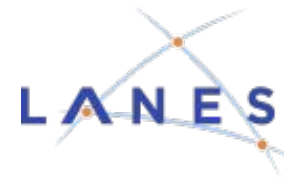
Building the MVP: Learnings

1. A range of channels are necessary because of the wide variety of capabilities of both senders and receivers of data (sFTP, HTTPS, MLLP, Direct, IHE, FHIR).

2. Minimum data standards for ADTs, beyond what DxF P&Ps require, is necessary to adequately support most use cases.

3. FHIR is faster to configure and test but requires well-defined use cases and workflows. Many systems have FHIR capability but very few are using it in production.

4. No majority-adopted workflow exists for clinical referrals let alone social care referrals, there are considerations required for consent and sharing data not covered under treatment.

5. Actors have limited bandwidth but would be prioritize social care use cases and/or testing with FHIR.

6. Need better way to do patient discovery and matching in the real world.

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DxF Community Sandbox Demo

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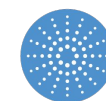
Update on Current Community Design Studio

| PICF Community Design Studio	Completed Steps	Next Steps
Partners in Care Foundation (PICF), partnering with: ● Prospect Medical CRC ● LANES ● PointClickCare ● LA Care ● Anthem ● Blue Shield Promise Plan	● **Sprint 0:** Introduction to use case design methodology and partner identification ● **Sprint 1:** Finalized a systems map of all stakeholders and technologies; Engaged and interviewed other stakeholders ● **Sprint 2**: Decided on an Acute Care Transition Use case; Developed Persona ● **Sprint 3**: Developed User Story and Use Case Scenes	● **Sprint 4:** Develop functional, system and information interchange requirements ● **Sprint 5:** Identify, and develop mitigation strategies for issues, risks and obstacles ● **Sprint 6:** Achieve consensus on the Use Case package and make Use Case accessible to the public

Lessons Learned:
- Making non-standard documents such as ECM Care Plans available to all care team members is critical.
- Portals are still used as a way to deliver ADT notifications and make documents available.
- Determining at point of care whether someone is already enrolled in ECM is difficult but QHIOs are helping
- Determining ECM eligibility at point of care and automating referral to ECM Providers is critical workflow.

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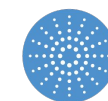Advancing data sharing to improve the health of all Californians
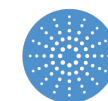
Next Community Design Studio

Sacramento Community Design Studio with a Housing Use Case to Launch in July 2024

Confirmed Partners
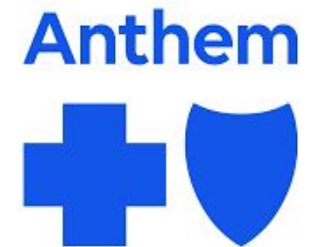
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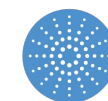Advancing data sharing to improve the health of all Californians

Call to Action

1. Sign the Data Sharing Agreement (DSA) and update your organization's exchange preferences in the Participant Directory – *Available Here*

2. Use the DxF Community Sandbox to find out who else in your community has signed the DSA that your organization can potentially partner with – *Coming Soon*

3. Develop use cases with peers and partners through the Community Design Studio – *Contact Us To Learn More*

4. Utilize CalAIM TA Marketplace Funding to engage with DxF Community Sandbox – *Available Here*

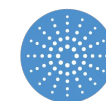Connecting for Better Health
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Available Technical Assistance

	Level of DxF Readiness	C4BH Supports	What it is	Outputs
1	**Planning**	**DxF Bootcamp**	Half day education of what the DxF is, overview of Policies and Procedures, and help with identifying priority use cases	Develop a DxF Roadmap and Identify Priority Use Cases
2	**Assessment**	**DxF Community Design Studio**	6-8 weekly sprints to design real-world community use cases	Technical and Functional data exchange workflows, test data and reports
3	**Ready to Connect!**	**DxF Community Sandbox**	Real-world testing environment for DxF priority use cases.	Test and Validate Use Case to Establish Workflows

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News, Events, and Announcements

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C4BH Storytelling – Call For Local Stories To Support AB 1331

DATA SHARING TO ASSIST CARE MANAGERS

Anwar Zoueihid
Vice President Long Term Services & Supports, Partners in Care Foundation

Anwar's Vision
A future of seamless and automated data exchange to support proactive and effective care coordination for patients

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2w · Edited · 🌐

Meet Kristen Valdes, the Founder and CEO at b.well Connected Health who knows the system inside and out. Despite this, her daughter Bailey nearly lost her life because her providers didn't have access to her full medical history, leading to a dangerous contraindication.

The California Data Exchange Framework (#DxF) mandates electronic sharing of health and social services information to enhance care coordination and public health. Despite this, 70% of required signatories have not complied. We must enact Assembly Bill 1331 to further establish a governance structure to hold entities accountable so patients, like Bailey, have full access to their health information.

More patient stories: https://lnkd.in/ebAa_T4Q

KRISTEN VALDES

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Stacey's life changed drastically after her first mammogram revealed she had breast cancer. Obtaining her medical records from local providers in California proved to be a significant challenge and when she sought additional information from a primary care practice in Colorado, she faced bureaucratic obstacles and unexpected fees. Stacey wishes that the exchange of information between providers could be instantaneous. The delays in receiving her historical medical information postponed her treatment, allowing the cancer to progress. She feels saddened and angry about a system that prevents individuals from taking ownership of their own medical history.

The Data Exchange Framework (#DxF) envisions a future in which all Californians and their care teams have access to the information they need for safe, effective, whole-person care. Assembly Bill 1331 will further establish a governance structure to strengthen the DxF so patients, like Stacey, have full access to their health information.

STACEY TINIANOV

Email olivia@connectingforbetterhealth.com to share a story or quote!

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What We're Reading – Check Out C4BH's Newsletter!

SOGI Data Considerations for State Medicaid Programs

CMS introduced new options for state Medicaid programs to collect sexual orientation and gender identity (SOGI) data to identify and address differences in LGBTQ+ health experiences and outcomes. As states seek to collect SOGI data, they should consider the purpose of it, staff training, and needed policy changes to prevent negative impacts. Read More

NYC Care Workers Demand More Detailed Overdose Data

Care workers in New York City are requesting state regulators to release data associated with drug overdoses to reveal emerging overdose trends in certain ethnic groups and neighborhoods. More granular data will allow for better allocation of services to prevent future overdoses. Read More
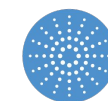
HRSA Health Center Program Implements FHIR-Based APIs

The Health Center Program between the ONC and HRSA is leveraging FHIR-based application programming interfaces (APIs) to support annual reporting. The advancement reduces reporting burden on physicians, enhances data quality, and informs quality improvement interventions to improve health outcomes and reduce health disparities on a federal level. Read More

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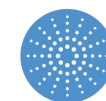
Upcoming Events

- **July 11, 12:30-3PM PT:** CalHHS DxF Implementation Advisory Committee | [Access the Meeting](#)

- **July 12, 10-11AM PT:** American Health Information Management Association | Screening for Social Drivers of Health: Lessons from the Field Webinar | [Register here](#)

- **July 18, 9-1:30PM PT:** HealthIMPACT & Answers Media Network | Measuring the Impact of AI in Healthcare Summit | [Register here](#)

- **September 27:** Community Clinic Association of Los Angeles County Health IT Summit | Los Angeles, CA | [Register here](#)

- **October 15-17:** Civitas Annual Conference | Detroit, MI | [Register here](#)

- **October 20-23:** HLTH 2024 | Las Vegas, NV | [Register here](#)

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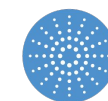Advancing data sharing to improve the health of all Californians

Announcement: July 11th Meeting Cancelled

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C4BH Technical Assistance and Sponsor Opportunities

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C4BH Annual Sponsor Tiers

Annual Sponsor Tiers *See next slide for exclusive sponsor benefits*	Platinum *$100,000+*	Gold *$50,000*	Silver *$25,000*	Supporters *$500*
End-of-Year Dinner	Table of 8-10 seats with recognition	4 seats with recognition	2 seats with recognition	Priority Invitation
Add Logo to Website and Sign-On Letters with Opt-Out Approach	✓	✓	✓	✓
Access to Office Hours	✓	✓	✓	✓
Advisory Group Representatives	1+	1	1	
Access to DxF Sandbox Community Studio	Priority Access	✓	✓	
Access to DxF Bootcamps	Priority Access	✓		
First Right to Engage in New C4BH Projects	✓			
White-Labeled DxF Implementation Toolkit	✓			

Do Your Priorities Differ From The Annual Sponsor Tiers? Reach Out To Us!

Additional Sponsor Opportunities Available For Our End-Of-Year Dinner On December 4th!

Appendix

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California Legislation Tracking: Key Dates

1. **July 3:** Last day for policy committees to meet and report bills and Summer Recess begins

2. **August 5:** Legislature reconvenes from Summer Recess

3. **August 23:** Last day to amend bills on the Floor

4. **August 31:** Last day to pass bills and Legislature adjourns

5. **September 30:** Last day for Governor to sign or veto bills

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